We're Spreading The Word...
In The Past Year We Have Reached More Than 300 Million People!

We’ve worked hard during the past year to raise public awareness about bone marrow diseases and our Foundation’s efforts to help those families battling these rare disorders. We want patients, caregivers, health care practitioners, and the general public to become aware of the need for greater research, the need for more blood and platelet donations, and the need for expanded advocacy. To this end we hired public relations firm, Environics Communications, to help develop our awareness efforts.

A news release was picked up by a variety of organizations, including CBS MarketWatch, DallasNews.com, Finance Canada, MedicalDevices.org, NBC6.com, National Hispanic Corporate Council, CNET.com and Yahoo!

Profiles of AA and MDS patients appeared in publications such as Family Support Magazine and on websites such as healthnewsdigest.com and applesforhealth.com. An interview/profile of AA&MDSIF President Bob Carroll, who is himself an MDS patient, appeared in For the Record and Senior Digest. The Foundation was profiled in Exceptional Parent in their organizational spotlight section. And, an article on ‘Coping with Rare Disease’ authored by Marilyn Baker is posted on the National Women’s Health Information Center’s Website, www.4women.gov <http://www.4women.gov/>, part of the U.S. Department of Health and Human Services, Office on Women’s Health. A shortened version of that article was also published in the Dallas Weekly and Philadelphia Public Record; and will appear in a fall/winter issue of Balance magazine.

AA&MDSIF advertisements have been seen in more than twenty magazines, including Redbook, PREVENTION, AARP Bulletin, MediZine, Vitality and Better Homes and Gardens.

Want to help in your hometown? Call the AA&MDSIF and we will help you to spread the word!
FROM THE DIRECTOR...

“We who lived in concentration camps can remember the men who walked through the huts comforting others, giving away their last piece of bread. They may have been few in number, but they offer sufficient proof that everything can be taken away from a man but one thing: the last of the human freedoms – to choose one’s attitude in any given set of circumstances, to choose one’s own way.” — Viktor E. Frankl

Control is such a huge issue for patients because we lose so much of it when we are ill. There are times when it seems that the disease controls every aspect of our lives from our bowels to our destiny. However, as Frankl stated above, our attitude about our disease, and how we manage it, is within our power. How we view the fact that we are alive - and what we do with the life that we have been given, whatever shape it is in, always remains within our command.

I wish I had a nickel for every family member or friend who has called me to comment on a patient’s behavior exclaiming, “But they’re not handling it right!” as if there was a right or wrong way to do battle with - or to accept - such a chronic and devastating disease. We each have a different style for handling crises, some pretty and some not so pretty. For the sake of those who love us and those who are trying to heal us, it would be nice if we were polite about our illness...you know, had some grace about feeling so crummy. It would be lovely if we all handled medical crises in a dignified and rational manner; but sometimes we don’t. It doesn’t matter how we cope with our illnesses because it is our human right to handle them any way we darn well please. This might mean taking a wild world cruise between doctor’s visits or sitting at home charting our blood counts. We can tell our family every tiny medical detail or we can tell them absolutely nothing. We can wisely treasure the blessing of each minute of life or we can lay in bed and whine about how we’ve been cheated. We can cry and scream or we can laugh and dance…and we can do it all at the same time if we want…and all of it is the right way to handle illness.

There are millions of patients in the United States who are living with a chronic disease. If you stop and think about it, this means that many of the people we meet everyday are in the same boat we are in...even if we can’t see that they are sick, they might be battling illness too. Realizing this can make us more aware of our common fragility - can make us more compassionate and tolerant toward others - and it might turn a simple act of kindness into an enormous act of brotherhood. All of this is within our control.

— Marilyn Baker, M.S.
Executive Director & Editor

THANKS TO...

The AA&MDSIF gives sincere thanks to Environics Communications for obtaining the following gifts:

♦ Kate’s Paperie in NY (paper products for Conference) www.katespaperie.com;
♦ Whole Foods Market (box lunches for Conference) www.wholefoods.com;
♦ Bear Naked Granola in CT (health food products for the Conference) www.bearnakedgranola.com
♦ MTV (more than 500 hats for patients undergoing treatment);
♦ Horizon Organic in CO (monetary donation).

CONFERENCE AUDIO TAPES AVAILABLE...

To receive a set of Conference tapes, please contact our office and give your name and postal mailing address. Our sincere thanks to Paul and Sheila Pearce of Piedmont, California for sponsoring the cost of these tapes.

GREAT WEBSITE...

www.faculty.fairfield.edu/fleitas/contents.html or search for “Bandaides and Blackboards”

This is an outstanding website for children and adults on growing up with medical problems...”The intent of the site is to sensitize people to what it’s like to grow up with a medical problem. Too often, youngsters so affected must cope with stigma as well as with their medical conditions. Teasing often accompanies this stigma, and adds a layer of pain to their experience of childhood. Unnecessary pain. Pain that isolates. Pain that affects not only the children who look or act or even just feel different, but all of the children in the classroom.”
If you are over 65 or disabled, you have been looking expectantly toward Washington, hoping that the Congress will pass a Medicare drug bill. This column will describe the basics of Medicare drug coverage and some possible improvements that might emerge from the current Congressional efforts. It also suggests some places you can turn to now for assistance if you have very large medication bills.

As it currently exists, Medicare pays for drugs differently, depending on whether you are a hospital inpatient, a hospital outpatient, in a physician office, or at the pharmacy. With a couple of exceptions mentioned below, if the drug is given by mouth (orally), it is not covered by Medicare. Similarly, drugs that you are picking up at the pharmacy are not covered. (nb: Many Medicare beneficiaries have purchased a type of “Medi-gap” insurance policy that includes additional drug coverage. The rest of this discussion assumes that you do not have such a policy.)

If you are a hospital inpatient covered by Medicare, then all of your medications are paid for. This includes all formulations, including oral dosages. You are responsible for deductibles and co-payments for the total cost of your hospital stay, but do not pay separately for drugs. The only limitation is that the drug must be prescribed by your physician or the hospital staff. Also, because of purchasing agreements and other considerations, a hospital might stock only a few of the medications in each therapeutic category and you may be given an alternative to the one your physician ordered.

Outside the hospital, Medicare only pays for drugs that require the assistance of a physician (or his/her staff under his/her supervision). This includes intravenous and infusion products, which usually are biologics, and precludes oral dosages of drugs. There is a narrow exception where Medicare will sometimes pay for the oral dosage if it is already paying for a physician-administered version of the drug.

Although the Medicare rules are quite complex, generally speaking a hospital will receive less for providing a covered drug in its outpatient clinic than a physician would receive for providing a covered drug in his/her office. As a result, patients may find that certain drugs and procedures may not be available in their local hospital outpatient department. This is likely to occur more often with drugs that treat rare diseases, such as aplastic anemia, MDS and PNH.

As Congress goes off for its August recess, the prospects for passage of a Medicare drug benefit are uncertain. Members of Congress know there is enormous pressure to pass legislation. However, there are substantial differences in the approach of the two bills.

The most important change, which would be accomplished by both bills, is the creation of a new Medicare Part D (part A covers hospital costs, part B covers outpatient costs). The new Medicare program would close the current gap by paying for outpatient drugs—oral formulations and drugs that you pick up at the pharmacy. The program would be voluntary (as is part B) and would cost about $35 per month in premiums. Low-income individuals would have their premiums subsidized.

The amount Medicare beneficiaries would need to spend before being reimbursed for drug costs varies between the two bills and can be confusing. While the final legislation may be different than either of the current bills, this chart allows comparison you’re your own drug expenses:

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<th>Senate Bill/ S. 1</th>
<th>House Bill/ H.R. 1</th>
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<tr>
<td>Initial deductible</td>
<td>$275</td>
<td>$250</td>
</tr>
<tr>
<td>Initial coverage</td>
<td>50% up to $4500 in total spending</td>
<td>80% up to $2000 in total spending</td>
</tr>
<tr>
<td>No Coverage</td>
<td>Next $1312</td>
<td>Next $2900</td>
</tr>
<tr>
<td>Catastrophic Coverage</td>
<td>90% after $3700 in out-of-pocket costs ($5800 in total spending)</td>
<td>100% after $3500 in out-of-pocket costs ($4900 in total spending)</td>
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Even if a Medicare drug benefit is adopted this year, the main features of the program will not be in place for at least two years. Therefore, if your medication bills are overwhelming, it is a good idea to look at other sources of help. There are at least three that you should consider:

- Medicaid. This is a federal/state program for low-income individuals and families. It covers most medical expenses, including medications. Many states also cover individuals who spend much on their medical expenses that they have little income left. Apply through your state’s Medicaid office.
- State pharmaceutical assistance programs. A number of states have a program separate from Medicaid that provides free or discounted medications. Most of these programs are aimed at low-income seniors, but a few have a broader scope. Inquire through your state’s department of health.
- Assistance programs sponsored by pharmaceutical companies. Most companies have programs, but the products covered, degree of subsidy, age and income requirements are all different. There are several sources for information, including company websites. A comprehensive site put together by the Pharmaceutical Research and Manufacturing Association is: http://www.helpingpatients.org. A Spanish language version is: http://espanol.helpingpatients.org/.

In addition, participants in clinical trials often have some of their medical care and medications taken care of. To qualify, you must meet the requirements of the trial. The ones that are relevant to aplastic anemia, MDS and PNH are listed on the AA&MDSIF website.

Interested in being of help with our advocacy effort? Join our grassroots advocacy network by sending me your name, address, phone, and e-mail address (very important). Starting this fall, we will be gearing up to push for appropriations language that will increase research into aplastic anemia, MDS, PNH and other bone marrow failure diseases. My e-mail address is: grossman@aamds.org.

Join me by contacting the AA&MDSIF today! Together, we can make a difference.
I am a 41 year old woman, wife and mother of four (Michael 16, Alex 15, Joey 14 and Lauren 7.) I was diagnosed with PNH (Paroxysmal Nocturnal Hemoglobinuria) in 1997. My biggest struggle has been balancing my health with being a wife and mother. I want to be the best mother I can be for my children, but having PNH does not always allow that. I expected I’d always be a devoted wife, taking care of my husband, but things have changed quite drastically for me.

This journey has been a long hard road, but it has changed my life in ways (both positive and negative) I could never have imagined. The single most important thing I have learned on this Journey is that you can’t move forward until you have acknowledged your present difficulties and weaknesses. For me, it was accepting that I have a chronic illness which ultimately may take my life. I decided I would control this disease rather than let the disease control me. I took matters into my own hands but it hasn’t always been that way...

In the beginning; I was angry. Angry at the world, angry at God but most of all angry at myself. I thought I must have done something to deserve this fate. This only created one thing: misery and depression. Now I was sick, miserable and depressed; not a very happy place to be. I realized I had a choice to make: I could stay where I was or adopt a healthy, fulfilling, productive lifestyle. I owed it to my husband, my children but most of all I owed it to myself to be at peace with it.

Any chronic health condition can be limiting, painful or fatiguing and requires a great deal of patience and strength to cope with the effects on your body. I knew I must learn some good self-care techniques as well as acknowledging limitations and restrictions in my life. I consulted with my health care providers to assist me in my journey. Together we were determined to achieve my goals.

I began with educating myself on my condition. I searched everywhere I could think of to help me learn and understand what effects PNH could have on me. I talk at length with my health care providers to better understand what they can do to help. I keep a weekly Journal so I can better remember good and bad events to relate to my medical team. In turn I have built a trusting bond with my physicians. I began to tell them what I expected out of myself, from them and most of all from the disease. I was no longer afraid; rather I was longing for more information. The more I knew; the stronger I felt. I joined a PNH Support group. Relating to others with a similar condition was a tremendous relief. They are a wealth of knowledge and unconditional love. I am thankful for the friends I have made in the support group. The more I learn the better I am able to relate to my children (age appropriately of course) what I can and cannot do for them. I am always honest with them. They began to ask more questions and thoughtful answers helped to allay their fears. My husband began to feel more comfortable with me and with the disease. He began to relax, communicating his fears and frustrations. He started to accompany me to all my appointments feeling more educated, asking more questions regarding future treatments, medications and limitations. He feels more supportive as my husband & more in control as a father. As a family we have grown closer to each other, more respectful of each other, but mostly more compassionate & loving toward each other. It is a sweet victory from something that I initially thought was so devastating.

When I started the quest to change my lifestyle, I had no idea how many changes I would go through. My Journey was now leading me into self discovery. I was now seeing what really mattered in life. I began to value my self on a new level. My success now was based on daily achievements rather than how much money I was earning and how many material items I gained. I began to “clean out the cobwebs.” I unloaded people and things that were weighing me down. I became more spiritual, often feeling blessed that I have the chance to recognize what’s really important in life. I know the true value of family and friends. They are priceless! I often let people know what they mean to me and how much I appreciate what they do for me. Life is truly short not because of a chronic disease but because we allow ourselves to become caught up with trivia rather than the natural joy of life. I now meditate each day, thankful for the person I have become. I take the time to stop & smell the roses because I didn’t do it enough. I take time to enjoy my children because housework can wait.

I take time to laugh with my husband because he deserves my time. I take time to visit with my family and friends because they matter to me. I don’t know how much time I have, but neither does anyone else. I choose to spend my time with those I love, those that matter most in life, my family.
Florentine Caminisch was born in 1906 with the type of dedicated team spirit that you don’t often find today. Florentine worked for PG&E for 44 years without ever taking off for a sick day! And when his county municipal couldn’t afford to pay to clear the way for a water pipeline, Florentine organized the community and neighbors to get their shovels out and dig the several miles needed to lay the pipes. Florentine passed away in 1988 but he made sure that his spirit lived on by directing his money to go to “helping aplastic anemia and to help the people that have it.” Florentine is still pitching in and helping even when he has passed on; what a true American Spirit.

The AA&MDSIF has used Florentine’s legacy wisely by creating the “Florentine Caminisch Research Award” which will provide support for 3 years to a worthy researcher studying bone marrow failure. The AA&MDSIF Scientific Review Committee review 10 applications and judged Dr. Monica Bessler’s study “Genes, Chromosomes and Bone Marrow Failure” as the most worthy of this award.

Upon hearing of the Committee’s decision, Dr. Bessler, assistant professor in Hematology at the Washington University School of Medicine, comments, “I am very excited and deeply honored to receive the “Florentine Camenisch Research Award” from the AA&MDSIF. Here at Washington University School of Medicine, St. Louis, a team of physicians, research scientists, medical geneticists, genetic counselors, nurses, and biostatisticians, along with doctors from other collaborating medical centers throughout the United States have initiated a new study to identify alterations in our genes that may predispose a person to develop a bone marrow failure disease — aplastic anemia, paroxysmal nocturnal hemoglobinuria (PNH) or myelodysplastic syndromes (MDS). We believe a genetic predisposition to aplastic anemia and myelodysplasia (MDS) is much more common than currently appreciated. By understanding the genetic contribution, we hope to gain a better understanding of the course of the disease and ultimately the factors that predict response to treatment.

The funding from this award will be essential in helping us to initiate this important collaborative effort, to invite individuals with bone marrow failure to participate in our study, and to initiate clinical testing for these gene alterations. We will gladly provide further information for interested individuals (mbessler@im.wustl.edu) and sincerely thank Florentine Camenisch, through the AA&MDSIF, for their help in our study and their generous support.”
What are the risks of the smallpox vaccine for patients with aplastic anemia and MDS? Should immunocompromised patients avoid contact with those who have received the smallpox vaccine?

Patients with compromised immune systems should NOT receive the smallpox vaccine. Additionally, they should avoid contact with persons who have received the vaccine.

There was little evidence in the past for smallpox (variola virus) or smallpox vaccine causing aplastic anemia. The smallpox vaccine has not been given in the US since the early 1970s. It is therefore not contributing to aplastic anemia occurring now. However, as with other viral infections, a person who already has aplastic anemia or MDS might be more susceptible to further marrow suppression. The smallpox vaccine is a live virus and vaccinated persons can pass the infection, particularly to an immunocompromised patient. Vaccinated individuals should not be in contact with immunocompromised patients until their skin vaccination site is completely healed.

**My doctor is recommending that I take Lipitor to control cholesterol. Are cholesterol medicines ill-advised for patients with bone marrow failure — aplastic anemia, MDS or PNH?**

Lipitor is not on the list of medicines that may suppress bone marrow. Each patient should discuss the risk-benefit ratio when deciding to treat a concurrent disease. In the case of elevated cholesterol, the doctor will want to take into consideration cholesterol levels and current status of bone marrow failure in the patient. Other approaches to lowering cholesterol may be worth investigating.

**My doctor is recommending that I take medicine to control high blood pressure. Are these medicines ill-advised for patients with bone marrow failure — aplastic anemia, MDS or PNH?**

Patients sometimes experience high blood pressure (hypertension) as a side effect of high dose steroids given at the time of ATG therapy or as a side effect of cyclosporine. Treatment depends on the severity of high blood pressure and the need for continued use of the drug. In the case of the latter, if the diastolic is greater than 90 or the systolic greater than 150, the doctor will review the trough cyclosporine levels to see if it could be decreased. Hypertension due to cyclosporine can be treated with calcium channel blockers, such as diltiazem (Cardizem CD, Cardizem SR, Dilacor XR, Tiazac). These drugs have the effect of increasing the cyclosporine levels, therefore cyclosporine levels should be monitored closely.

Some patients may develop high blood pressure independent of medications they are taking. In those cases, the doctor must balance the degree of hypertension vs. the small risk of additional medicine causing worse marrow failure. In general, patients who have bone marrow failure diseases should use medications only when really necessary.

**APLASTIC ANEMIA**


**MDS**


**IRON OVERLOAD**


**RECENT MEDICAL LITERATURE**

Listed below are a few recently published journal articles indexed in the National Library of Medicine database MEDLINE at www.pubmed.gov. To obtain complete articles, contact your public or hospital library.

**APLASTIC ANEMIA**


**MDS**


**IRON OVERLOAD**


ANNUAL PATIENT CONFERENCE

Nearly 300 patients and their families gathered in San Francisco to make friends, exchange information, and hear presentations from some of the country’s leading medical experts. Our thanks to photographer Neil Cuadra!
THE MARY PAT PORTSHIRT

How many times have you as a patient with a central line or Portacath wished you could go for a blood test or transfusion without having to change into a patient gown? Often the temperature in the treatment room is chilly making it even more uncomfortable wearing a patient gown.

Mary Pat Griesshaber solved this problem by designing a medical access shirt. The Mary Pat Portshirt provides medical personnel easy access to a central line or implanted port for blood draws, transfusions, chemotherapy without having to remove the patient’s shirt or expose the entire chest.

Mary Pat dealt with aplastic anemia for ten years had an implanted portacath for six years. Her nurses often asked her, “where did you buy your shirt?” “It makes it so easy for us, and adds to your comfort as well.”

The Mary Pat Portshirt is now available to all patients who would also like to streamline their port access. It is available in black or white, adult sizes: S, M, L & XL for $35, plus shipping.

The Earl J. Goldberg Aplastic Anemia Foundation, an affiliate of AA&MDSIF is handling the sale of this item.

All profits from the sale of The Mary Pat Portshirt will be donated toward bone marrow failure research.

For information e-mail Portshirt@aol.com or phone EJGAAF at 1-847-559-0688.

Aplastic Anemia & MDS International Foundation, Inc.
P.O. Box 613
Annapolis, Maryland 21404-0613
(800) 747-2820 fax (410) 867-0240
help@aamds.org www.aamds.org

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All donations received by December 31st will be acknowledged in our Annual Report and End-Of-Year Thanks published in our Winter Newsletter for annual donations over $500.

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The AA&MDSIF is solely supported through individual contributions and is a non-profit charitable organization as described under the Internal Revenue Code, Section 501(C)(3).

For more information, please call the AA&MDSIF at: 800.747.2820 or 410.867.0242 or help@aamds.org

Know Where Your Money Is Going...

The American Institute of Philanthropy has determined that the reasonable industry standard for administrative and fundraising expenses is a maximum of 40%. The AA&MDSIF is proud to spend only 8%. Please compare our performance with other organizations when making your annual charitable contribution.

<table>
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<tr>
<th>Administrative Expenses</th>
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Patient Support & Research 92%